

# Aging with Disability: Implications for Policy and Public Programs

Joshua M. Wiener, Ph.D.
RTI International
Washington, DC

www.rti.org

#### Introduction

- In part due to medical advances, younger people with disabilities are living longer, many becoming elderly
- Older people are living longer as well, many living with a disability for extended period of time
- Trends raise questions about traditional separation of programs by age
  - Separation standard in most countries (e.g., Australia)
  - Rationale for providing services to people at 65, but not at 64?
  - Initiatives include Administration for Community Living, consolidation of Medicaid HCBS waivers, reorganizations of state bureaucracies



# Typology of People Aging with Disability

When Became Disabled and How	Low Income Starting pre- 65	Low-Income Starting post 65	Not Low Income
Post age 65			
Pre age 65, disabled at birth or when young			
Pre age 65, disabled when adult			

# **Problems and Programs**

- Labor force participation and income support
  - Disability Insurance and Social Security
  - Supplemental Security Income
- Long-Term Services and Supports
  - Private long-term care insurance and CLASS Act
  - Medicaid
  - Administration on Aging/ACL
- Medical care
  - Private health insurance
  - Medicare
  - Medicaid



# Labor Force Participation and Income Support



- Elderly model involves long period of work and asset accumulation, which then use in retirement
- Key issue: How do you structure programs to encourage work, while at same time provide adequate level of income support to people who cannot work
- Employment rate among working age people with daily activities disability was 11.6% in 2010 (Kaye, 2010)
- During recession, job losses among workers with disabilities far exceeded those of workers without disabilities
- In 2010, 35% of people with disabilities below 150% of federal poverty level vs. 20% for people with no disabilities

# Change in Income and Net Worth among People age 70 and Older in 1993, by Disability Status in 2002, in Constant Dollars

Change in Financial Status	No Disabilities in 2002	Disabled in 2002
Income, 1992- 2001	\$1,420	\$ 147
Total Household Net Worth, 1993-2002	12,044	\$-22,773

Source: Johnson and Wiener, 2006



# **Social Security Disability Insurance**

- In 1960, about 1% of individuals 25-64 were on SSDI; in 2009, 4.5%.
- Disability Insurance trust fund projected run dry by 2016 (Social Security Trustees, 2012)
- During economic downturn, Disability Insurance
   Claims have increased by 25%
- In 2012, average benefit \$1,110 per month
- People aging into Social Security receive same benefit amount
- After 2 years eligible for Medicare



# Social Security Disability Insurance (cont.)

- Disability Insurance conceives of working and disability as two completely distinct states
- Does not help people return to work; less than 1% of people on Disability Insurance return to work per year; once on, age into Social Security
- No incentives for employers to implement changes that enable employees with work limitations to stay on the job
- Application process onerous, so not want to give up
- Ticket work and other incentives have failed
- Research suggests substantial negative effect of DI rules on work effort (Maestas and Song, 2011)



# **Supplemental Security Income**

- Aged, blind and disabled
- For low income people with few assets, with little or no work history—e.g., people with congenital disabilities, such as people with intellectual disabilities
- Definition of disability same as Social Security Disability Insurance
- Average \$500 per month for individual in 2010
- Key to Medicaid eligibility



# **Supplemental Security Income (cont.)**

#### Issues

- Few people leave Supplemental Security Income
- Initiatives, such as Section 1619(a) and (b) of Social Security Act, have failed to get people into labor force
- Importance of Medicaid for long-term services and supports and medical care
- People live a lifetime of poverty with no hope of doing better
- Financial asset eligibility levels of \$2,000 for individual not raised since 1984



# **Medical Care**



- Many, but not all, people with disabilities have serious medical problems
- Additional chronic illnesses as age and medical problems of underlying disability: e.g., down syndrome and dementia,
- Some high disability diseases are degenerative, e.g., multiple sclerosis and Alzheimer's disease, and become more severe over time
- Subtracting out "normal costs," disability associated medical expenditures were approximately \$200 billion in 2006 (Anderson et al., 2006)



# **Background (cont.)**

- In 2007, 37% of community-dwelling Americans with disabilities were obese vs. 27% of the population. Obese people with disabilities had almost three times (\$2,459) the additional average cost of obese people without disabilities (\$889) (Anderson et al., 2011)
- Because of Medicare and Medicaid, uninsurance is lower among people with disabilities than people without disabilities (U.S. Bureau of the Census, 2011)
- Uninsured individuals with disabilities confront significantly more barriers to accessing care than do nondisabled persons without health insurance (lezzoni, Frakt, and Pizer, 2011)



### **Private Health Insurance**

- Acute model: get sick, get treated, get well
- Medical underwriting for individual policies
- Pre-existing condition exclusions
- High cost of policies



# **Private Health Insurance (cont.)**

- For people with disabilities, always have their preexisting conditions and diagnoses
- Affordable Care Act address by prohibiting medical underwriting and pre-existing condition exclusions, giving people with disabilities access to health insurance on the same basis as people without disabilities
- Hard or impossible to do without everyone in the insurance pool



#### Medicare

#### **Background**

- People on Social Security Disability Insurance after 2 year waiting period. About 10% of Medicare eligibles
- Covers a broad range of services, including rehabilitation, skilled nursing facilities, home health, durable medical equipment

- Substantial deductibles and coinsurance: Hospital deductible is \$1,156; Part B premiums is \$99.90 per month
- Covers post-acute care, not long-term services and supports
- Fragmented care



#### **Medicaid**

#### **Background**

- For low-income people with disabilities who do not have Medicare, primary source of medical care is Medicaid
- Payment levels usually lower than private insurance and Medicare

- Access to services can be problematic
- Fragmented care
- Among dual eligible Medicaid HCBS waiver beneficiaries, 250-408 potentially avoidable hospitalizations per 1,000 person years (Walsh et al., 2010)



# Medicaid (cont.)

- Medicare/Medicaid Dual Eligibles demonstration:
   Integrates acute and long-term care in a capitated or managed fee-for-service setting:
  - Do providers and managed care organizations know how to manage care for this population?
  - Will integration save money and improve care and how will we know?
  - Will integration overmedicalize long-term care?
  - Will people lose their choice of providers in managed care organizations?
  - How will states and federal government monitor these initiatives?

# **Long-Term Services and Supports**



- Principal sources of help vary greatly by age: parents dominates people under age 30; between ages 30 and 74, spouse is main source of help. For people aged 75 and older, daughters and sons become the principal unpaid caregivers. (Kaye, Harrington and LaPlante, 2010)
- Non-elderly adults less likely to receive paid care in community than elderly population. 15% for 18-64 compared to 29 percent for older people
- Philosophy of consumer-directed services enormously influential for older as well as younger people with disabilities



# Private Long-Term Care Insurance

#### **Background**

- About 10% older people have private long-term care insurance, but about 2% of population age 20 and older (Feder, Friedland and Komisar, 2007)
- Policies are expensive and medically underwritten
- Market is in trouble with major companies withdrawing

- Need services now, not in future
- People with disabilities cannot buy because of medical underwriting
- Cannot afford policies



# **CLASS Act**

- Voluntary long-term care insurance program in Affordable Care Act
- Completely self-financed by premiums
- No medical underwriting
- Limited to working population
- October 2011, HHS announced would not implement because it would not be financially viable



#### **Class Act**

- No mandatory enrollment and adverse selection drive up premiums
- Weak work requirement in place of medical underwritting to accommodate people with disabilities drive up premiums
- Lifetime benefits to meet needs of people with disabilities drive up premiums



#### **Medicaid**

#### **Background**

- Main source of financing for long-term services and supports
- Must be poor or become poor in order to receive services

- Number of non-elderly Medicaid nursing home residents is increasing, while decreasing for older people
- People age out of EPSDT at age 21
- Not eligible for Older Americans Act services until 60
- Medicaid spend down vs. poor all along



# Medicaid (cont.)

Parents growing old for people with intellectual disabilities

